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**Seeking out very like-minded others: Exploring trust and advice issues in an online health support group**

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**Abstract**

Online health communities are one source of information and advice in which people, patients and their carers can exchange information and experiential advice. This advice is likely to be mixed in nature with some congenial i.e. supportive of a person's existing standpoint and some uncongenial. This study examines how people manage the process of advice giving in a cancer support group. A discourse analysis of data collected from an online message forum explores how participants manage to ask for and offer advice within a peer setting. The findings highlight a group who collectively see advice giving as one of their key functions and have developed mechanisms for portraying their competence and trustworthiness. Advice seekers use their initial message as a positioning statement to indicate the boundaries associated with their decision making and the parameters within which advice givers are permitted to operate. Members use a number of discursive techniques to deal with uncongenial advice including, humour, alignment with unnamed others and the presentation of idiosyncratic reasoning. Seeking out very like-minded others provides support and reinforcement for pre-existing views. The results are discussed in terms of the role of online health communities in decision making.

**Keywords**

**Online communities, health, Internet, trust, decision making, discourse**

## 1. Introduction

Online health communities are one source of information and advice in which people, patients and their carers can exchange information and experiential advice. A number of studies have documented the social and emotional support these communities offer their members. There are online social support groups for a range of health conditions including sports injuries (Preece, 1999), irritable bowel syndrome and infertility (Coulson, 2005; Malik & Coulson, 2008) and groups specifically designed to provide support for friends, family and other caregivers (White & Dorman, 2000) but there has been little attention given to the influence they exert in terms of decision making. A review of the literature concerning online cancer support suggested that participation in such groups helped people cope more effectively with the disease (Klemm et al. 2003). However, other studies have indicated that whilst the Internet can increase patients' knowledge about their health conditions, they can be left feeling too overwhelmed by the information available online to be able to make an informed decision about their own health care (Hart, Henwood, & Wyatt, 2004).

We know that when faced with risky health decisions people use a number of trust markers to process the websites and the advice they encounter. These markers include the design features of the site, the perceived expertise of the material and the extent to which the site is personalised (Fogg et al. 2002 Bhattacharjee, 2002; Briggs, De Angeli & Simpson, 2004). Recent research has indicated that one important marker appears to be the extent to which the advice supports the person's pre-existing viewpoint (Sillence et al., 2007). In a study looking at women's use of the Internet in making decisions about hormone replacement therapy (HRT) and alternative treatments the authors noted that women were often motivated to seek information and advice that supported their own viewpoint and used this to build confidence in their decision making. For example one participant reported "I wasn't too keen on HRT before and I'm certainly not now" after reading information on a number of websites. Such identity preferences are consistent with self-verification theory (Swann & Read, 1981), which explicitly predicts that people will seek the advice of others whose experiences and beliefs overlap with their own.

The range of health websites available is vast and the way people search for information and advice online means that they are exposed to material of varying quality (Briggs et al., 2002). We know that experts and consumers differ in the way they search for and evaluate sites (Standford et al, 2002). Consumers it appears take a broader perspective on the nature of expertise as a trust factor, valuing lay expertise or experiential advice as well as medical expertise. This is reflected in online health usage patterns over recent years. Users are moving away from more institutional led sites (e.g. those provider by Governments and health care providers) towards more experiential or community sites providing a peer focus (Sillence et al, 2007b). In these sites everyone is an expert in their own health issues and experience provides the underlying basis for expertise.

Web based communities then offer several advantages to the health consumer. Online social support can reduce feelings of isolation and can provide information and emotional support (Preece, 1999). Some web based communities offer a very focused perspective on a particular health issue whilst others provide a place for all viewpoints to be aired and discussed. In terms of decision making web communities offer patient experience which is often case based, usually vivid and perhaps more easily accessible than numerical information presented on more institutionalised sites. This may present the decision maker with somewhat of a double edge sword. In general people encountering an online health

community are likely to be faced with a wide range of opinions and information on the health topic some of which is congenial (i.e. matches their pre-existing beliefs) and some of which is not. How then do they negotiate the process of giving and receiving advice in this setting? This is the focus of the current study which explores how people contributing to a prostate cancer message forum assess the trustworthiness of the information and advice they encounter in this community site and to what extent the messages influence decision making?

## **2. Prostate cancer as a focus for decision making**

In the UK prostate cancer is now the most common cancer in men excluding non melanoma skin cancer (Sinfield et al., 2008). Worldwide, more than 670,000 men are diagnosed with prostate cancer each year (Cancer Research UK, 2008). Men are faced with a number of risky decisions regarding prostate cancer both before and after diagnosis and have to evaluate the trustworthiness of the information and advice they receive from a number of sources including the Internet. The screening test for prostate cancer (Prostate Specific Antigen, PSA test) is now widely used but its value in diagnosing prostate cancer in asymptomatic men is controversial (Chapple et al., 2008). Both false positive and false negative results are relatively common. After diagnosis men are faced with decisions concerning their treatment options. These include active surveillance (no active treatment), radiotherapy and hormone therapy and surgery. Many of the treatments have comparable efficacy but differing side effects e.g. impotence and urinary incontinence (Gwede et al., 2005) making decisions difficult. The situation is often made more complex by the fact that the cancer has a relatively slow growth rate, thus making it difficult to quantify the risk of mortality. This means that many prostate cancers are not life threatening and treatment for men in this category may provide no potential benefit (Australian Cancer Network, 2002). In addition some people are given few options or none at all (some specialists make the treatment decision without explanation or discussion (Sinfield et al, 2008)).

Research so far on decision making for prostate cancer patients has shown that in general men do not tend to use information about medical treatments in a comprehensive or systematic manner. Decision making processes are biased by pre-existing beliefs about cancer and health (Steginga et al., 2002). Prostate cancer support groups are rated highly by their members (Steginga et al., 2005) although clinicians are concerned that these groups might offer men misleading information support particularly for treatment choices (Steginga et al., 2007). Access to experiential Internet based information has shown to be valued amongst cancer patients (Rozmovits & Ziebland, 2004) and Steginga and colleagues (2002) noted that 73% of men had sought information from external sources primarily the Internet followed by friends and family.

## **3. Managing the process of giving and receiving advice in an online community**

Advice has been defined as ‘opinions or counsel given by people who perceive themselves as knowledgeable, and/or who the advice seeker may think are credible, trustworthy and reliable’ (DeCapua & Dunham, 1993, p519). This definition highlights the asymmetry of the relationship involved in the advising process and points to the difficulties involved for both parties in managing the interaction. For the advice seeker, asking for advice is in a way undermining their identity as a competent person, playing down their own knowledge and

abilities. They have to expose themselves to the risk that comes with trusting another person's judgement and direction. The advice giver is not immune from the difficulties inherent in the situation. They have to demonstrate they are worthy of offering advice. This involves establishing credibility and trust via expertise (amongst other things). Advice givers also have to pay attention to the cues of the advice seeker. They have to be sensitive to their needs. It is not always easy to recognise the fact that someone is asking for advice. The way in which that advice is presented is crucial as well if the giver is to succeed in passing on his or her way of thinking on the topic. Because this asymmetry between the players in the situation is potentially difficult or could even be perceived as threatening, the context may require that the advice giving will require mitigation rather than being a straightforward offering. Locher & Hoffman (2006) suggest that such mitigation may for example occur in the form of humour or through the use of lexical hedges such as 'maybe' or perhaps'.

The literature on expert advice giving has mostly concentrated on face to face settings (see for example Silverman's work on counselling, 1997). Other researchers have focussed on written expert advice often in the form of agony aunt style personal problem pages in newspapers, magazines or online (see for example Locher & Hoffman's (2006) study on a fictional online advisor, providing expert advice for a university health service.) A feature of expert advice columns or websites is that the answers represent solicited advice. DeCapua and Huber (1995) point out that in solicited advice authority is granted to the advisor by the advisee. This might be the case, for example, in traditional doctor-patient interactions but is the same true in online communities comprising of peers? The question of authority itself is a more difficult situation within peer settings. Lamerichs (2003) in her PhD thesis examining online depression support groups highlights a number of factors that make the process of managing advice more complex online. Firstly the nature of the medium makes the process of developing trust and portraying expertise more difficult. Visual cues and other physical markers and checks of trust (e.g. gender, age, location etc) are obviously absent. Richardson (2003) notes that credibility and trust are central to whether an individual's contribution to a newsgroup is accepted or not. In her studies users engaged in 'warranting strategies', i.e., in strategies 'designed to give fellow participants reasons to take the information seriously', for example by referring to (presumably reputable) sources. Sillence et al., (2004) also noted that a positive trust marker was the extent to which sites allowed and encouraged cross referencing.

Expertise is not straightforward within peer settings (Lamerichs, 2003). Unlike the traditional health advisory discourse in which there is one expert advisor i.e. the medical profession and one lay advice seeker i.e. the patient, online peer support groups are by their nature a community of supposedly equal peers. Initially (and potentially for the duration of the community) there is no strict expertise hierarchy or outright entitlement to expert status. The language used to manage the advice giving process is thus crucial. There will be variations in the expertise on offer in web communities and differing viewpoints making the advice giving process complex. Indeed Lamerichs (2003) noted that within the community she was studying the members did not explicitly ask for advice nor did the community as a whole see it as one of their primary functions. The aim of the current study is to explore the trust and advice issues associated with a peer support group. Do members ask for advice overtly? If so how is the process managed interactionally? Do members trust the information and advice available and to what extent are people seeking out very like-minded people?

#### **4. Methodology**

Having received ethical approval from the School's ethics committee the author collected, over a three month period, postings to an online message board discussing prostate cancer. The message posts were taken from three of the board's forums and contained entire thread sequences, i.e. the full set of messages and replies around a particular posting. 15 threads containing over 350 messages were retrieved and examined. Two threads were analysed in detail. These threads contained 42 and 46 messages respectively from 15 and 17 separate participants. Details of the forum headings are not given nor the site identified to protect the anonymity of the posters.

The author is concerned with the way in which talk is used to perform particular actions such as requesting, refuting and blaming. To this end a discursive analysis of the message postings was undertaken. Discourse analysis involves an examination of how people use language to construct and make sense of the situation (Potter & Wetherell, 1987). For the purposes of this study discourse was taken to 'refer to a group of ideas or patterned ways of thinking which can be identified in textual and verbal communications and located in wider social structures' (Lupton, 1992). Discourse or language does things e.g. it biases, it persuades etc and it achieves this through the deployment of discursive practices. Using certain words, metaphors, rhetorical styles and terms of reference allow the phenomenon, in this case advice giving, as a social object. The social object is thus constructed by the language, the choice of description and associations it makes explicit or implicit. It is argued that these choices are important, they are not neutral and do not simply just happen.

In a broad sense this study explores the resources and associated social practices involved in asking for and offering advice in the context of an online message forum discussing prostate cancer. This involves a fine-grained analysis of the detail of text with a view to examining the particular discursive resources which have been deployed, and the ends to which they have been put. To this end the messages have not been edited for spelling etc and any capitalisation is left as in the original message. Names and any other personal identifiers e.g. age; location, hospitals and consultants names have been altered to protect anonymity.

#### **5. Results**

The findings are presented in two parts. The first part presents the strategies used by the group that contribute to developing a trustworthy site and providing prostate cancer patients with a site for 'someone like them'. The second section presents a more in-depth analysis of postings taken from two different threads in which the original posters come to the message boards asking for advice.

##### **Section 1: We are someone like you - providing a trustworthy site**

Before presenting the results it is important to stress that within this particular online health community people do ask for and offer advice. As previous research has shown (e.g. Lamerichs, 2003) this is not always the case within online groups. Within the context of advice giving there are variations and subtleties in the way such processes are managed interactionally and the results section will highlight these.

This group then collectively sees itself as a place in which members can expect to ask for and receive information and advice. Indeed this is a function which is taken seriously by the

group as a whole. Whilst this is recognised as a club, a friendly supportive place it is also a serious place where the process of giving advice is not taken lightly. The community does not present itself as an alternative to the medical profession but neither does it suggest to its members that the medical profession is the only source of expert and credible advice available. Members are vocal in demanding the best for one another and if that means asking for a second opinion or encouraging each other to question received (offline) wisdom then they do not shy away from saying so. However there is something about the way in which the community draws on the medical discourse that adds to their credibility. For example, members will demand certain pieces of information from a poster before any advice is provided. They carry out what is akin to a doctor taking a thorough medical history of his or her patient as highlighted in [1].

[1]

The consensus is that you put a little detail in your profile, like PSA, Gleason Grade, T stage etc, this allows fellow sufferer's to swap notes and experiences etc in a meaningful way.

Like any community there is a common language which supports and underpins the group. Members who respond to requests for advice use a number of warranting strategies (Richardson, 2003) to indicate their credibility and suitability for the task. These include presenting their own history and experiences through the profiles and the message posts, presenting their own key statistics and making reference to other websites and sources of information.

The site appears to draw strength from the fact that it is a (somewhat reluctant) 'club' made up of individuals. So although collectively they strive to provide a common place to share advice and experiences they recognise that individual members are all different and as such will have different experiences and viewpoints to draw upon. These differences are dealt with in a respectful way and seen as a strength in terms of the breadth of advice that can be drawn upon. Furthermore although everyone in the community has the same reason for being there the group as a whole recognise their limitations in that ultimately any decisions that need to be made have to be made by the individual and not the group. Members recognise longevity and expertise amongst the rest of the group and are very honest about the limitations of their own expertise. Members often report the boundaries of their own personal, first-hand experience, see [2].

[2]

I can't personally advise you on 'active surveillance', as my own options on diagnosis were limited, but I know you'll get plenty of views, advice and experiences from other members of our 'club'.

So on the one hand, the community offers readers a place for people 'like them'. A collection of people who have first-hand experience of the issues they are dealing with. They are a trustworthy group, a group that takes its role seriously, a group that bases advice on sound knowledge of the condition and, as a result of note taking, on the individual member concerned. Yet the group recognises its own limitations in terms of individual expertise and individual preferences, everyone is different.

## Section 2: Asking for advice?

In this section messages belonging to two single threads are presented. Both threads begin with a newcomer asking the group for advice. In each of the opening messages the newcomers present their cases and ask for advice in very different ways. As the message threads continue it is possible to see the ways in which the two advice seekers position themselves for advice, integrate and contrast the advice with offline sources and deal with uncongenial advice.

### Case 1: Seeking to draw on some of the wisdom out there

In this thread the new member BS posts a message to the group asking for advice concerning a treatment approach that he is currently considering. The opening lines show the way in which the poster presents himself as someone trying to learn from the group and their collective experience.

#### *Positioning oneself for advice*

[01BS]

- (i) Hi, I'm new to this forum so please excuse ignorance - particularly if I'm revisiting old
- (ii) ground for many of you, but am seeking to draw on some of the wisdom out there.

<Here BS details some of the procedures he has currently undergone culminating in the diagnosis of prostate cancer>

- (iii) They have already said my options are limited. I'm contemplating the 'active surveillance'
- (iv) approach unless medical consensus is that this would be very unwise. Q.: Has anybody
- (v) else out there either gone down this route, or know of anybody who did ... and what were
- (vi) the outcomes or conclusions? How quickly can the c. develop from festering away
- (vii) peacefully, to suddenly breaking out... and is it then always too late to contain it? Look
- (viii) forward to any advice, and please be as frank and robust as you like.....

In this post BS begins his opening message by stating that he is new to the forum. He asks the community to '*excuse his ignorance*' (line i) and contrasts his somewhat lowly position with the '*wisdom*' that's out there (line ii). Initially at least BS is setting up the traditional expert – lay person advisory context and advising the group of his intention to make use of some of their expertise. The qualifier '*some*' (line ii) gives us the first indication that BS is not completely without knowledge himself and suggests that not all advice and opinion will be welcome or perhaps acceptable. After detailing his diagnosis of prostate cancer (PC) he switches to talk about treatment options. 'They' (line iii) by which we assume he is referring to medical professionals have already discussed his limited treatment options. BS says that he is '*contemplating active surveillance*' (line iii) suggesting that his mind is not already made up. Although in the same line he provides the community with the parameters by which he would alter his thinking in terms of this treatment path, '*unless medical consensus is that this would be very unwise*' (line iv). This sentence is quite key to this positioning message. Firstly we have already through his use of the pronoun '*they*' that BS does not seem overly deferential to medics yet here we see him setting medical parameters around his decision making. He is careful to qualify this statement. The need for a '*consensus*' about the decision being '*very*' unwise makes it somewhat more difficult for medics to achieve these criteria. The sentence also alerts the community to the fact that BS has a strong position on this issue, one that they will find difficult to alter. BS however is keen to hear from very like-minded



people, people who have been down the active surveillance route and or know others who have. Finally he ends his opening message with a call to the whole community to offer any advice and not to hold back in their views and opinions.

BS's positioning message has an almost challenging feel to it, something which occurs again with more force later on (see 03BS). To this first post BS receives 5 replies (2 asking for more medical information) 1 saying hello and 2 providing an indication that they had chosen active surveillance and providing some background information. When BS posts again it is in response to the information from someone who had started on the active surveillance path.

[02BS]

- (i) Well, lots of very quick but highly informative browsing (thanks MJF!) and so far,
- (ii) hardening ever further in favour of active surveillance....pinning everything on hope that
- (iii) the last psa was artificially high courtesy of inflammation or infection....What I'm
- (iv) totally failing to understand, is why hardly anybody seems to go down the active
- (v) surveillance route ? Locally, seems that everybody diagnosed leaps straight into a
- (vi) treatment regime, despite the widely advertised downsides. I really must be missing
- (vii) something fundamental....

BS begins this post by making a direct reference to the information sources recommended by a fellow active surveillance poster, line i – '*thanks MJF!*' The phrase '*lots of very quick but highly informative browsing*' (line i) suggests that BS was engaged in scanning the website sources rather than reading information in any detail. This could (in conjunction with the fact that he is '*hardening even further*' – line ii) indicate that he is scanning over information which is already familiar and positive in terms of his current decision making. BS then ponders on the question of active surveillance and its low take up. He gives the impression that he is still giving careful thought to the approach and this contrasts with other people who perhaps make hasty decisions '*everybody diagnosed leaps straight into a treatment regime*' (lines v- vi). He is careful to distinguish this '*everybody*' that he refers to from the other members on the message board. '*Locally*' (line v) makes the distinction between his offline environment and the message board. He plays down his own understanding and thus his robust opinion, in the form of a challenge '*I really must be missing something fundamental*' (line vii). Later on in message [03BS] BS issues a far more direct challenge to all community members along the same lines.

[03BS]

- (i) It's all looking good for now....however ... if anybody out there believes I'm still being
- (ii) unwise contemplating this 'do nothing' strategy, please do chirp up ?

The term 'unwise' (line ii) reminds us of his positioning message [01BS] in which he contrasted himself excuse ignorance with the wisdom out there. Here he is reminding the group of the relative positions. Again he refers to his '*Contemplating*' (line ii) as in the first message despite the fact that we have seen his position '*hardening*' [02BS]. The most noticeable feature of this message however is the deliberate and purposeful use of the term '*do nothing strategy*' (line ii). As a proponent of the AS approach he will be aware of the fact that it does not involve doing nothing and that this phrase is more likely to be used by

someone less inclined to support the approach. The contrast here is provoking and indeed provokes a response.

[04BB]

- (i) Personally I'm not a fan of "doing nothing" but given your PSA and Gleason it's certainly
- (ii) worth considering. I had no choice. If I had your results I would probably still go for an
- (iii) active cure, only because of your age. If you were 10 years older I would not.

In message [04BB] the poster responds directly to the '*do nothing*' challenge. He makes it clear that this is not an option he favours either in a general sense '*I'm not a fan of doing nothing*' (line i) or for himself specifically. The poster indicates that AS was not an option for him, medical circumstances ruled it out '*I had no choice*' (line ii). Although this means that BB believes that BS does have the option to '*do nothing*' it is something he would still not advocate. He presents this advice through a hypothetical '*If I had your results*' phrase (line ii). This approach provides a less directive form of advice although the intention is still quite clear, despite the qualifier '*probably*' (line ii). References to age indicate that the poster has been following the thread and provide some reasoning for his indirect advice. Again '*doing nothing*' (line i) is contrasted with an '*active cure*' (line iii).

### ***Reporting interactions with doctors***

So far BS has been following two clear lines of discourse. The first is almost a challenge to the community to find fault with his reasoning over the decision to go with AS. The second is the medical undercurrent i.e. that only medical opinion (not the board's opinion) or medical fact might force his hand and force him to make a different (unwelcome) decision to try some form of active treatment. So how does he report his interactions with his doctors and manage to maintain his standpoint?

[05BS]

- (i) At this week's (second) meeting with the Oncols they were now definitely inclined
- (ii) towards treatment rather than supporting AS, Naturally, Dr. BS is countering that the
- (iii) wayward psa is simply due to chronic inflammation....

[06BS]

- (i) Both Oncols and Surgeons have expressed a firm inclination towards treatment so looks
- (ii) like they'd all prefer me to submit to RP, and pretty soon. Gold Standard....here we come
- (iii) ?? Well, no. Somewhat stubbornly, not about to change my thinking re. AS just yet !
- (iv) You guys out there keep saying that there's no real need for hasty decisions in this game
- (v) ...sincerely hope that's right.....Others have already said 'just get it out while you still
- (vi) can'....

In message [05BS] BS refers to himself as '*Dr BS*' (line ii). Of course he is aware that the community know that he is not a doctor but this touch of humour serves to a) diffuse the uncongenial message that he is getting from his doctors regarding his treatment choices and b) says something about the importance he attaches to knowing oneself in this case. In message [06BS] again employs humour as a way of playing down the importance of uncongenial information by referring to the decision making process as a '*game*' (line iv). BS explains that medical opinion is now firmly inclined towards treatment and that his doctors would prefer him to undergo surgery. The first part of the message builds up towards a

picture of this happening and ends with a question, is BB about to follow medical advice (as he indicated he would in his positioning message [01BS] '*Well no*' (line iii). The second half of the message indicates that he is not about to change his position. He draws on the advice provided on the message board in support of his decision. He refers to '*you guys out there*' (line iv), the online community which has repeatedly provided information that supports his decision thus far '*keep saying that there's no real need for hasty decisions*' (line iv). He is (choosing) to trust their advice over other, uncongenial advice but accepts that in trusting their advice he puts himself in a vulnerable position '*sincerely hope that's right*' (line v). His description of the online community is friendly and relatively specific, this contrasts with the unspecified '*others*' (line v) which have given him the opposite advice. BB has however been presented with uncongenial advice messages on the board so how has he dealt with that?

### ***Dealing with uncongenial information and advice***

In BS's first positioning message he made it clear to everyone that he welcomed '*frank and robust advice*' from the community. In message [07GT] we see a direct challenge to BS's decision making re: active surveillance from someone who chose the polar opposite (?) decision – surgery or '*the chop*' (line i). The acronym '*ASAP*' (line i) again contrasts with the waiting approach of AS.

[07GT]

- (i) I cannot help on the AS question as I went for the chop ASAP! In your case I'm not sure
- (ii) what the downside is for you in not having the surgery. From what you have said you
- (iii) seem to be suffering some very nasty effects from the condition of your Prostate. What is
- (iv) your reason for not wanting rid of something that is giving you so much aggro?

[08GT]

- (i) I'm somewhat confused at your reasons for being so resistant to RP and continued faith in
- (ii) AS.

GT's use of the word 'faith' (line i) conjures up images of belief in the face of rational thought. He then goes on to ask if the concern relates to a common side effect of surgery, loss of sexual function. This direct, indeed GT apologies for being so blunt, approach appears to force a response from BS.

[09BS]

- (i) GT...it's a question you have raised before, and the answer certainly lies within that
- (ii) territory. These issues are still very important to many of those afflicted, and many will
- (iii) have been more than slightly traumatised to be in the position of even contemplating 'impairment'.

BS is not as explicit in his response '*answer lies within that territory*' (lines i-ii). In responding to this uncongenial message BS draws on a wider group of like-minded patients in support of his standpoint. Whilst GT's messages appear to suggest that there is something idiosyncratic about BS's position BS himself uses the power of numbers to indicate that he is not alone in his thinking '*These issues are still very important to many of those afflicted*' (line ii).

### **Case 2: I can't help worrying that's just how I am**

In this series of extracts the newcomer DD has just been diagnosed with PC. It was a borderline diagnosis and whilst he indicates that the prevailing view from the message board for someone in his position is to slow down and take their time making decisions DD does not feel this is something he is able to do.

### ***Positioning oneself for advice***

[01DD]

- (i) Of course as my problem appears to be small at the moment I could just do nothing, but
- (ii) my head is telling me that is not really an option as I know it will always be in the back of
- (iii) my mind. Also what's to say it won't suddenly decide to get going and I've missed the
- (iv) boat. I know having read other posts many people say don't be in a rush but I can't help
- (v) worrying, that's just how I am. ....If anyone has any words of advice (I'm not asking you
- (vi) to tell me what I should do) I would be very grateful.

Once again if we examine this positioning message we can see that a lot of stance taking is going on here. Unlike the opening post from the first thread, in which BS was almost provoking the community to contradict him, DD is quite defensive in making clear both his preferences in terms of treatment and the response parameters from the message board. The question of *doing nothing* (line i) is once again of paramount importance. Unlike BS, DD uses the phrase without the inverted commas, he is not deliberately trying to be controversial here or trying to provoke argument. He sees doing nothing as simply doing nothing rather than engaging in active surveillance. Contrast '*I could just do nothing*' (line i) with '*my head is telling me that is not really an option*' (lines i-ii). The juxtaposition of these two statements highlights DD's thinking. The first phrase represents a knee jerk reaction, an initial, ill considered option. Whereas the second phrase indicates that the do nothing option does not stand up to DD's careful scrutiny. DD makes it clear that some of his thoughts may not be open to change but are simply elements of his personality and basic make up '*I can't help worrying, that's just how I am*' (lines iv-v). As with the opening post from BS, DD asks explicitly for advice, from '*anyone*' however he uses a heavy qualifier, '*I'm not asking you to tell me what to do*' (lines v-vi). This contrasts with BS's call to be '*as frank and robust as you like*.'

The responses to this initial posting all reinforce the message not to make any hasty decisions. Both 02VG and 03NY are quite robust in providing DD with the message that there is no need to rush or hurry in terms of making a decision. 03NY emphasises the point with capitals and 02VG produces a list like set of tasks for DD to undertake. This is practical advice in the sense that there is something constructive that DD can be getting on with. It also serves to reinforce the idea that there are a lot of things to think about before making a hasty decision. This list of tasks will by its nature slow DD down and force a delay to his decision making as there will be '*masses of information to absorb*' (line iv). Ultimately however, 02VG appears to recognise the immovable nature of DD and ends his post by contrasting '*judgement*' and '*instinct*' (line v). 04BR himself adopting the active surveillance approach points DD towards some information regarding the approach. Being able to present information in this way highlights the expert nature of the advisor and acts as a warranting strategy (Richardson, 2003).

[02VG]

- (i) There is no need at all to rush. If you see my profile, I waited some time, this seems to be
- (ii) more of an accepted approach than it was 3 or 4 years ago. My advice is to research all the

- (iii) options fully, speak to as many professionals as you can, also look at this site and ask
- (iv) questions. You will have masses of information to absorb and your decision will be based
- (v) on your judgement of this information. Trust your instinct and go with what you feel is
- (vi) right for you.

[03NY]

- (i) As VG said - THERE IS NO HURRY - prostate cancer cells grow very slowly. Take you
- (ii) time in choosing your treatment path. As the beastie has been diagnosed very early you
- (iii) have an EXCELLENT chance of getting rid of it.

[04BR]

- (i) Don't dismiss out-of-hand the "Active Monitoring" route. The "Tool Kit" on the main web
- (ii) site has a good fact sheet about this at <web ref>, there's also a separate fact sheet "Active
- (iii) surveillance - Questions to ask your doctor".

### ***Reactions to offline medical advice***

DD posts a new message this time reporting on his visit to his doctor. In post 05DD the theme of time is present once again as DD worries about leaving things '*too late*' (line iv)

[05DD]

- (i) My visit to the Doctor this morning has helped me come to what I think is the right
- (ii) decision based on the information I have available to me at this time. I have just about
- (iii) ruled out 'Active Monitoring' as I'm the sort of person that I'm afraid does worry about
- (iv) things. Whatever I do I don't want to leave it too late - there I go again on the worry
- (v) machine! Having talked things through with my Doctor it seems that if I went down the
- (vi) RT route it would rule out an op later on. Brachytherapy is also out for the same reasons.
- (vii) That leaves me with the op! Would it be better to have an op now rather than leave it,
- (viii) just keeping a check on my PSA. What flaws can you see in my reasoning and what
- (ix) have I not thought about.

In this posting DD begins by explaining that he has come to '*the right decision*' (lines i-ii). There are two noticeable features about this statement. The first is the role of the Doctor mentioned in line i. The doctor is given a capital letter 'D' which strengthens the obvious importance that DD places on their role in coming to the *right decision*. Other treatments stand in the way of an operation – *the op* (line vii) so attention switches to whether it is better to have the operation now or to wait a while. The operation seems like a good solution to someone who *worries about things* and doesn't want to *leave things*. The second noticeable feature is the obsession with time. DD is making the decision based on the information available *at this time* (line ii). There is something very much of the present about DD's postings, decisions have to be made here and now. This goes against the advice offered earlier suggesting that the wait would increase the amount of useful information on which to base a decision. Lines viii – ix offer a challenge to the community members to spot any flaws in DD's reasoning. The fact that a lot of DD's reasoning is covered by his self professed idiosyncrasies '*I'm the sort of person that I'm afraid does worry about things*' (line iii) makes it difficult to challenge or to offer advice in general. However DD's reliance on his doctor is one situation that a community member feels able to comment upon more directly. Again the

message is offered as a word of caution, a message to slow down. He questions DD indirectly by questioning the expertise and authority of the doctor explicitly.

[06VG]

- (i) You say you talked to your Doctor. Is that your GP, or a consultant in the urology
- (ii) department of your hospital? If it's your GP, then do get a second opinion from another
- (iii) neurology consultant. If it's a consultant, then ditto! (No reflection on your GP, by the
- (iv) way, but their role is to diagnose a condition and send you to the right consultant in such
- (v) a case, not to prescribe such specialist treatment.)

### ***Keeping the decision making process alive?***

In DD's first, positioning post he made it clear that 'doing nothing' was not an option. Through his discussions with his doctor [05DD] he talked about coming to the 'right decision' although towards the end of that post he back tracked a little and invited others to point out any flaws in his thinking. Whilst it is possible to see how DD has already in effect made his made up to have the operation it is apparent in the following three posts [07 -09DD] how important it is for DD to present the decision making process as still alive to other members.

[07DD]

- (i) Just to let you know I've made no firm decision yet!

[08DD]

- (i) I don't think I would be able, realistically, to wait for as long as you have before taking
- (ii) some sort of action. A fluctuation in my PSA would be a real concern if I did nothing. On
- (iii) the other hand the possible consequences are quite daunting.
- (iv) I think before I make any decision I need to first of all talk to a surgeon as I'm still of the
- (v) opinion I need to 'get rid' for my own peace of mind. This may be seen to be too hasty by
- (vi) others, but it's just how I feel at the moment.
- (vii) Perhaps things will change over the course of time.

[09DD]

- (i) Have an appointment with Oncologist on 10<sup>th</sup> September so will report progress after that.
- (ii) Then it's decision time I guess

The three posts although reported in chronological order present different accounts of the finality of the decision that DD has made. DD moves from not having made a *firm* decision to not having made any decision to identifying the time when he can make (or express/execute his decision). Post [08DD] gives us another chance to examine how DD manages the decision making process. Contrast the definite '*real*' concern (line ii) with the much more qualified 'possible' and 'quite' (in line iii). Although DD presents what a first glance appears to be a balanced argument the contrast reveals the dislike for the active surveillance approach. Whilst the details of the negative associations with active surveillance are spelled out e.g. '*a fluctuation in my PSA*' (line ii), the potential side effects of surgery are not specified at all, just left as '*possible consequences*' (line iii) thus rendering them somehow less likely? DD indicates that he needs to '*get rid*' (line v) referring to a sense of finality concerning surgery

as an option. He has not managed to really find any very like-minded others on the site (at least none that have posted) but distances himself from making this comparison too confrontational by using the less personal 'others' in the statement '*this may be seen to be too hasty by others*' (lines v- vi).

## 6. Discussion

It is an accepted feature and function of this online health community to provide their members, when asked to do so, with information and advice. The advice giving process is one that is taken seriously with members adopting a quasi medical discourse in the form of rigorous and thorough medical note taking. Advice givers present advice within the limits of their own experience and within the boundaries set by the advice seekers themselves. Members are engaged in the discursive business of giving views but recognise that different people have different opinions both on and off the site. Advice givers have to strike a balance between presenting their own fairly forceful opinions and appearing to be dogmatic. They use a variety of techniques to achieve this including drawing on the power of the collective group e.g. 'the consensus here on the board is that,' encouraging advice seekers to think through their position by answering a series of questions and using hypothetical scenarios e.g. 'If I had your results...' People inject humour into their advice and rely on devices such as lexical hedges. In this community as in other advisory contexts (e.g. Silverman et al., 1997) members often focus on the transfer of factual information, e.g. lists of possible treatments or information on how the Gleason score is calculated. This provides one way of introducing and dealing with sensitive issues in a more detached more neutral fashion and thus a less directive manner. In general the style of the community is to be non directive in its approach to advice giving. In that way this group belongs to an expert health advice discourse that exists in written form (Locher & Hoffmann, 2006) and in some offline medical situations, for example e.g. antenatal screening and testing (Williams, Alderson & Farsides, 2002). That is not to say that the content of advice is ambiguous or vague. Members' responses can be direct and fairly specific but are delivered in such a way as to leave the seeker free to choose whether or not to follow the advice. Despite it being a peer community of 'like-minded individuals' the group recognises that decision making is a very individual process and that the advice seeker and only the advice seeker can make any final decision.

So then how do people ask for advice in the first instance? The initial post to the message board appears to be very important both for the advice seeker and any potential advice giver. In this first 'positioning' message the newcomer can detail their situation, provide some clues as to their current thinking or viewpoint and set the parameters by which advice givers can operate. Both advice seekers presented in the results defined the ways in which they were willing to receive advice. For one, BS, he positioned himself ready to deal with any challenge to his considered treatment position. DD was more prescriptive, stating that he did not want people to tell him what to do. The positioning message gives an indication of the member's current decision processes. In the results section we see two different advice seekers making very different decisions about treatment. Although both members explicitly ask for advice in their initial posting they both indicate that they have made at least an initial decision regarding treatment. During the course of the message threads neither member changes their opinion and this raises two interesting points. Firstly the importance of keeping the decision making process alive and secondly the way in which advice seekers deal with uncongenial messages i.e. information and advice which does not fit or support their current thinking with respect to decision making.

In responding to advice and presenting an account of their decision making thus far advice seekers are careful to ensure they present at least a little of the uncongenial information themselves in order to keep the decision making process alive. In presenting a forceful fully committed opinion any potential advice giver would see little point in trying to offer advice or indeed to needing to. A series of contrasting statements keeps the options open and indicates to readers that it is still worth engaging in the process of advice giving. When a member becomes a little too forceful backtracking can be seen to occur to re-engage the other members.

Advice seekers were exposed to information and advice that did not fit with their current decision making and thus can be seen as uncongenial. How did they deal with messages they did not want to hear? It is perhaps easier in an online setting to simply ignore messages you do not want to hear. BS was selective in terms of the messages he responded to and only replied to the member questioning his reasoning after they had posted a second more direct message. BS also guarded against uncongenial information through humour and through a purposeful adaptation of medical terminology. BS sought to add credibility to his position in the face of uncongenial advice by aligning himself to unnamed others thus making it clear that he was not alone in his thinking and so almost turning the tables on the poster. DD on the other hand makes a statement about his idiosyncratic thinking as a way of dealing with uncongenial advice.

Although the community is periodically reminded that the decision making process is ongoing, both advice seekers held strong opinions from the outset and did not engage with uncongenial information. If this is a widespread phenomenon then what can we say about the role of these message boards in health decision making? Advice seekers respond to the support offered by community members and acknowledge the considered thoughts and opinions expressed in message posts. Members offering advice wish to portray a sense of trustworthiness and use a number of warranting strategies (Richardson, 2003) to achieve these objectives. So in the eyes of the advice seeker wishing to make a decision this site is aimed at someone 'like them' and offers credible, trustworthy advice. However we have seen that members are most likely to act on the advice of a very like-minded other or at least are more likely to respond to their messages. Advice from very like-minded others is used to support and reinforce decision making offline in terms of interactions with doctors. Uncongenial information from less like-minded others is not trusted in the same way and is usually rejected or refuted. DD did not really encounter any advice from very like-minded individuals on the message board finding his trustworthy congenial messages in his interactions with medical professionals offline.

Clinicians have raised concerns regarding the influence of peer support on treatment decisions (Steginga et al., 2007). Peer support in an online setting raises further issues concerning the establishment of credibility and the provision of trustworthy advice. Given that people are making use of these community sites it is useful to note the following two points from this study. Firstly that this community takes its role very seriously and follows something of a medical approach to the provision of good quality information and advice that in addition to being experiential in nature is also well referenced. Secondly people are to some extent selecting congenial advice to support and reinforce their existing positions where the underlying decision making process appears to be based on a number of different factors including medical heuristics – deferral to clinicians and pre-existing beliefs about cancer (Steginga et al, 2002). Whilst this study only provides a snapshot of a single online health



community it highlights several ways in which a group of peers engage in the advice giving process. Understanding more about the ways in which experiential advice is used by patients in their medical decision making is of great interest to the medical profession, health charities and social scientists alike.

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